401 Scandinavian Nurse Specialist Group/Cystic Fibrosis (SNSG/CF)

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Aims: SNSG/CF was established to stimulate and improve cooperation between CF nurses from Scandinavian CF centers.
Methods: SNSG/CF includes all the CF centers in Norway (Oslo and Bergen), Sweden (Stockholm, Gothenburg, Lund and Uppsala) and Denmark (Copenhagen and Aarhus). The board of SNSG/CF comprises one CF nurse from each of the centers. The board meets twice a year to plan workshops and courses. SNSG/CF is part of the International Nurse Specialist Group/Cystic Fibrosis (INSG/CF).
Results: Within the framework of SNSG/CF a 2-day workshop is held every second year for approximately 40 Scandinavian CF nurses. A twelve-day CF course equivalent to 5 ECTS has been held once. Twenty-one nurses, physiotherapists and dieticians attended the course and the course will be repeated. SNSG/CF plans to make a common Scandinavian database on nursing interventions in CF. SNSG/CF aims to conduct common Scandinavian studies on nursing to the CF patient.
Conclusions: SNSG/CF is a good framework for cooperating and exchange of experiences.

402 Parental involvement, does this continue in adulthood?

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Introduction: Many parents feel that they will become excluded from the management of their child's care following transition, as the move from paediatric to adult care involves taking responsibility and becoming independent.
Aim: To explore parental involvement in their adult child's disease management.
Method: An audit of telephone calls made to the CF nurse specialist team over a period of four months was carried out. This involved recording: number of calls, identity of caller, age of patient, gender of patient, and what was the telephone call was about.
Results: Total number of calls: 405, number of calls made on behalf of patients: 127 (32%). Caller identity: mothers – 79%, fathers – 7%, partners – 9%, others– –5%. Age range of patients: 17–56 yrs (mean age: 23 yrs). Gender: male – 48%. Reasons for calls made on behalf of patients included: Patient feeling unwell, advice sought. Asking for recent sputum microbiology or blood test results. Making outpatient appointments.
Conclusion: One third of all telephone enquiries were made on behalf of a patient, almost all from parents (86%) with only 9% from partners. It appears that although the majority of parents have disengaged themselves from their adult child's CF management, a significant number continue to be actively involved. Professionals working in adult CF teams need to be aware that following transition from paediatric to adult care, a large number of parents continue to play an active role in CF management throughout their child's life.

403* A survey of self medication in an adult Cystic Fibrosis centre

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Aims: Our Trust operates a self-medication policy; patients bring their medication into hospital and nurses/pharmacist assess their ability to self medicate. We wished to determine patients' willingness to self medicate and their knowledge and understanding of their drugs.
Methods: A structured questionnaire of 20 questions was administered to determine their willingness to self medicate and their understanding of administration, action and side effects of oral (O), intravenous (IV) nebulised (N) and inhaled (I) drugs.
Results: 45 patients completed the questionnaire, 90% were happy to self medicate with N and I, 50% with O and IV. 60% of patients stated they understood what their medication was for, 30% had limited knowledge and 10% no knowledge. 90% knew when to take O medication, 90% how to take IV, I and N. 50% were aware of side effects and 25% had no knowledge. 50% had been shown how to administer their IV treatment within the last year, 15% within the last 2 years, 20% over 3 years, 10% regularly and 5% did not know. 55% had been shown how to administer N in the last year, 25% within the last 2 years, 15% over 3 years and 5% regularly. 40% had been shown how to administer I within the last year, 20% within the last 2 years, 35% over 3 years, 5% regularly. 50% would like more information about IV, 40% O, 30% N, and 35% I. 45% wanted more information about side effects, 15% how to take, 20% best time to take and 5% how to clean N.
Conclusion: This survey identified that patients are more reluctant to self medicate with O and IV medication than I and N. It highlighted patients' wishes for greater information on why they are prescribed some of their treatment and potential side effects. It has identified educational needs regarding administration of I, N and IV.

404 Review of a bereavement service for families of adult CF people

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Introduction: Providing help and support to CF families following bereavement is an important aspect of the CF nurse specialists' role. In 2002 we formalized this service to ensure a structured response to bereavement, including visits before the funeral and 2–4 weeks later, and telephone contact at 3–6 months. We wanted to determine if relatives were happy with the level of service, and that they were coping with their loss.
Method: In 2005 we audited the service provided between 2002 and 2004 to 16 CF families. All were offered a home visit and invited to complete an anonymous questionnaire, asking questions about the visits they received, the advice given, the offer of further bereavement support, the opportunity to discuss the death with the medical team, and the duration of support needed after bereavement.
Results: 9 families (56%) did not reply. Of the remaining 7, 3 (43%) requested a home visit and 5 (71%) returned the questionnaire. All had received 2 post bereavement visits, commenting that they were timely. All had received advice about equipment return, financial assistance with funeral expenses and information about support from professional bereavement counseling. One had taken this up for a year after her daughters' death. All were offered information about their relatives' death and 1 mother returned up to 3 years after her sons' death for this purpose. All stated they had been adequately supported by CF Nurse Specialists, with 2 requesting a final visit at 6 months. All said the visits were helpful but requested written information to augment information given early in the grieving process.
Conclusion: This study shows that many families still require help some years after the death of their CF relative, and this aspect of CF care should not be forgotten.